

REPORT TO THE IOWA GENERAL ASSEMBLY

**ANATOMICAL GIFT PUBLIC AWARENESS
ANNUAL DONATION AND COMPLIANCE REPORT**

FOR THE CALENDAR YEAR 2010

Submitted by

Iowa Department of Public Health

in conjunction with

Iowa Donor Network and Iowa Lions Eye Bank

Introduction

In 1996, the Iowa legislature created the Anatomical Gift Public Awareness and Transplantation Fund. County treasurers seek contributions to the fund when Iowans register or renew motor vehicle registrations. In 2004, an organ and tissue donation awareness license plate was created for Iowa motorists. A \$35 charge for the plate plus \$10 renewal fee, in addition to the normal fee, is provided to the awareness fund.

Iowa is served by one organ procurement organization, the Iowa Donor Network (IDN), and a single eye recovery agency, the Iowa Lions Eye Bank (ILEB). Through a contract with ILEB, IDN serves as Iowa's human tissue (eyes, bone, skin, tendons and heart valves) referral agency. ILEB conducts cornea recovery, processing, evaluation, and distribution services. Both organizations cooperate closely with Iowa hospitals to promote and accomplish organ, tissue, and eye donations.

Iowa Code Chapter 142C.17 requires the Iowa Department of Public Health, in conjunction with any statewide organ procurement organization, to submit an annual donation and compliance report.

Organs, Tissues, and Eye Donors

The number of Iowa organ donors for January through September of each year is as follows:

Year	Number of <i>Organ</i> Donors
2010	50
2009	43
2008	47
2007	42

The number of tissue donors, January through September:

Year	Number of <i>Tissue</i> Donors
2010	390
2009	412
2008	300
2007	264

The number of eye transplant and research donors, January through September:

Year	Number of <i>Eye Transplant</i> Donors	Number of <i>Eye Research</i> Donors
2010	737	368
2009	621	260
2008	506	274
2007	403	236

Organ, Tissue, and Eye Donors

Consistent with requirements of CMS, the Centers for Medicare and Medicaid Services, the Iowa Donor Network receives a referral call on every death in Iowa hospitals. Not every referral results in a donation. Consent for donation and medical suitability must also be considered.

On average, *each tissue donor* provides enough transplantable tissue for up to 50 people. It is projected that approximately 20,000 people will receive transplantable tissue needed for life-saving and life-enhancing procedures each year.

On average, *each eye donation* provides sight to two people and provides additional tissue for up to six scleral patch grafts for eye traumas and glaucoma shunt surgeries. In the past few years, corneal transplant surgical techniques have advanced and now provide options that improve visual outcomes in a shorter period of time. For example, through standard transplant techniques, 13% of patients achieve 20/40 vision or better in one year. This compares to 35% in three months using the new technique. The Iowa Lions Eye Bank is researching a new advance that has resulted in 20/40 vision or better within one month of transplant. Transplants are being performed earlier and more frequently than before, saving sight earlier and decreasing the trauma and loss of productivity of losing sight. Even though donations are increasing, they do not keep up with the demand in Iowa. In 2010, Iowa imported 48 corneas for transplantation and 19 eyes for research.

Eyes donated to research by Iowans are given to the University of Iowa John and Marcia Carver Center for Macular Degeneration. This year, donated eyes contributed to advances in three areas of blinding eye disease:

- Glaucoma researchers searching for the mechanisms that activate glaucoma discovered through their work with mice that an inappropriate activation of the immune system may be responsible. They are now utilizing donated human eyes to determine if that same immune system process activates glaucoma in people. Glaucoma is the leading cause of blindness in the world.
- Investigation of genetic defects causing blinding eye diseases in humans has resulted in clinical trials of the first genetic intervention for Leber's Congenital Amaurosis (LCA). LCA is a currently untreatable hereditary condition that causes severe vision loss and blindness in infants and children. Three young adults, aged 22, 25, and 25, legally blind since birth due to a specific form of LCA, have been receiving gene therapy. Preliminary one-year results show the three patients to be healthy and maintaining previous visual gains. "These results are very significant because they represent one of the first steps toward the clinical use of gene therapy for an inherited form of blindness," said National Eye Institute NEI director Paul A. Sieving, M.D., Ph.D. "I anticipate that it is only a matter of time before similar techniques will be applied to other genetic diseases affecting vision."

- Age Related Macular Degeneration researchers have discovered one pathway for activation of the disease. They hope to have treatment available in the near future that will stop macular degeneration in more than 70% of the people affected. The pathway appears to also play a role in heart disease, Alzheimer's, and abdominal aortic aneurysms.

Medicare Rules

In August 1998, the Health Care Financing Administration (now CMS, the Centers for Medicare and Medicaid Services) promulgated regulations designed to increase organ tissue and eye donation. The rules, part of the Hospital Conditions of Participation for the Medicare and Medicaid Programs, require "a hospital to have an agreement with the Organ Procurement Organization (OPO) designated by the Secretary of the Department of Health and Human Services (DHHS), under which the hospital will contact the OPO in a timely manner about individuals who die, or whose deaths are imminent in the hospital. The OPO will then determine each individual's medical suitability for donation. The hospital must also have an agreement with at least one tissue bank and at least one eye bank to cooperate in the retrieval, processing, preservation, storage and distribution of tissue and eyes, as long as the agreement does not interfere with organ donation. The final rule requires a hospital to ensure, in collaboration with the OPO with which it has an agreement; the family of every potential donor is informed of its option to donate organs or tissues or eyes, or not to donate."

Contributions

Contributions provided through county treasurers and the license plate program to the Anatomical Gift Public Awareness and Transplantation Funds totaled \$70,287 in fiscal year 2009. This is \$1,211 more than provided in fiscal year 2008. This revenue represents a steady rate of \$0.023 per capita (based on estimated 2009 population of 3,007,856 per the U.S. Census Bureau). County treasurers, IDN, ILEB, and IDPH continue to explore ways to increase awareness of the contribution opportunity and contributions to the fund.

Community Grants

Payment from the Anatomical Gift Public Awareness and Transplantation Fund totaled \$122,386 in fiscal year 2010. This included public awareness activities, organ transplantation procedures and related patient costs, and support of the donor registry. Of these payments, \$265 was spent to cover administrative costs.

The Anatomical Gift Public Awareness Advisory Committee established in 1996 ceased to be a program requirement, effective July 1, 2010. Iowa Department of Public Health gratefully recognizes the guidance historically provided by Advisory Committee members.

Donor Registry

Chapter 1052, Acts of the 2000 General Assembly, authorized the director of IDPH to contract for the establishment of a statewide organ and tissue donor registry. The contract provides for a centralized database and automated system to make organ, tissue, and eye donor information available to family members and physicians seven days a week, twenty-four hours a day. IDN launched the Iowa Donor Registry (www.iowadonorregistry.org) on March 18, 2002. To date, more than 1 million Iowans have registered their intentions to become organ, tissue, and eye donors upon death. In 2007, the Revised Uniform Anatomical Gift Act was passed by the legislature requiring the Iowa Department of Transportation (DOT) to provide the Iowa Donor Registry a listing of every Iowan who marked “yes” to donation on a license, permit or identification card. DOT provides monthly downloads to the Iowa Donor Registry as legal consent for donation according to Iowa law. This important legislation increased the number of registrants in the Iowa Donor Registry from an average of 2,000 entries per month to over 30,000 per month.

In September 2009, IDN was recognized nationally as the only organ procurement organization in the country to obtain three national benchmarks set forth by DHHS. In addition, IDN helped four Iowa hospitals receive gold and silver medals for their commitment to organ, tissue, and eye donation services.

Summary

Organ, tissue, and eye donation programs continue to serve a significant number of Iowans. As of November 2010, more than 580 Iowans are waiting for lifesaving organ transplants. This number is higher than the number waiting at this time last year. New corneal transplant techniques are being performed earlier in the course of a blinding eye disease, increasing the demand for corneal tissue. Researchers are testing genetic therapy for blinding eye disease. Efforts to increase public awareness and acceptance of organ, tissue, and eye donation must continue and should be fostered by every practicing nurse, physician, social worker, paramedic, law enforcement official, hospital administrator and funeral director in Iowa. The Iowa Donor Network, the Iowa Lions Eye Bank, and the Iowa Department of Public Health will continue to promote organ, tissue, and eye donation and explore ways to increase public awareness of the opportunity to donate.